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ABSTRACT

This paper reviews current demographic and programmatic trends with respect to the frail elderly. These trends include the projected growth in population of those 65 and older between now and 2030; the rapidly improving economic status of the older adult population and its effect on views of what the elderly's share of public money should be; the increasing diversity, fragmentation, and complexity of the gerontological services network and its effect on this cohort; the needs of growing numbers of third and fourth generation families that are unable to care for the needs of their 85-and-older relatives; and the questionable quality, inadequate funding, and resulting stigma attached to many existing community services. It is noted that community workers are also challenged by recent technological advances in community-based treatment, such as the wide range of in-home advanced medical and communication technologies now available to the elderly. In light of these trends, the paper addresses questions of staffing, training, and organizational design for services and makes suggestions concerning the future design of community-based care for the oldest old. References are included. (TE)

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The Future of Community-Based Services for the Old-Old: Technological and Ethical Challenges*

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The Future of Community-Based Services for the Old-Old: Technological and Ethical Challenges*

Introduction

Concern over the challenges we will confront as the numbers of old-old continue to grow is not as recent a phenomenon as one might think. Since its beginnings in 1974, the Federal Council on the Aging has directed its attention to that group of elderly - usually the oldest of the old - which it came to call the "frail elderly" (Federal Council on Aging, 1978). At that time, this target group consisted of persons, usually but not always, over the age of 75, who because of an accumulation of various continuing problems ofter required one or more supportive services in order to cope with daily life.

The Federal Council on Aging's concern for this cohort of elders arose in large part due to the fact that they comprised the major age grouping in nursing homes which were, at that time, coming under fire because of dissatisfaction with the quality of care in a number of these facilities. Consequently, a movement arose not only to improve institutional care - but also, in many cases, to avoid it altogether with community-based alternatives. It should be noted, that the Federal Council, almost 15 years ago, recognized that their were no simple courses of action that would successfully finance, plan and deliver a package of services to the frail elderly (that is, the old-old). The Council also acknowledged that such a package of services was not necessarily conceived to be comprised of health services alone, but rather represented a combination of health, social, income maintenance, and housing interventions.

Fifteen years after the Federal Council on Aging issued its position on public policy and the frail elderly, a series of demographic and programmatic trends have fully blossomed, placing additional pressure on our capacity to meet the needs of the eldest of Americans by means of community-based services.

First, is the mushrooming numbers of older persons in this country. Twenty-eight million people, more than one in ten Americans, are now over 65 years of age (Kasper, 1988). Fueled by the interplay among fertility, mortality, and migration rates, America's age profile is expected to continue to change markedly over the next several decades as the post-war "baby-boomers" enter their retirement years (Zopf, Jr., 1986). By the year 2030, 20% of the population will be 65 years or older, and because of dramatic gains in life expectancy (for white females in particular), the elderly population will be increasingly comprised of people 75 years of age and older (National Center for Health Statistics, 1987; U.S. Bureau of the Census, 1987). Significant gains in life expectancy have, in fact, forced us to redefine who we mean by the oldest-old. It is now the 85 and older population which is separated out as being most likely to be in need of formal supports and they, represent the fastest growing group of all. By the middle of the 21st century, 16 million Americans are expected to be 85 years of age or over, compared with 2.2 million in 1980 and 4.9 million in the year 2000 (Kasper, 1988). And, more Americans than ever before are entering the ranks of the centenarians, those living to be 100 years old (Walker and Harper, 1986).

The second trend is the rapidly improving economic status

of the older adult population and the impact this phenomenon is having on views of what the elderly's equitable share of the public dollar should be. Improved economic wellbeing among the elderly has, rather abruptly, forced us to more precisely measure relative wellbeing across the diverse subgroups of the elderly population. The poverty rate for those persons 65 years and over is actually slightly lower than that of the population as a whole. Yet, wealth is not evenly distributed across all cohorts of older adults. Thus, substantial numbers of economically deprived older Americans remain (the most vulnerable being elderly widows, the very old, those living alone, and members of minorities). And it is expected that the relative economic health of these groups will remain slow to improve in the immediate future, especially in the case of unmarried and divorced women (Bould, Sanborn, and Reif, 1989).

Furthermore, it is worth noting that there is a goodly measure of controversy over the relative sensitivity of federal measures of poverty to the needs of different age cohorts. In particular, there are those who argue that official measures of poverty do not adequately recognize the extra costs which frequently accrue to the aged population (i.e., special dietary requirements and higher health and medical costs) and thus calculated elder poverty rates may not be a wholly accurate measure of the economic status of older Americans.

The increasing complexity and growing difficulties in maneuvering about the gerontological services network is a third trend which is directly impacting on the old-old. Services to the aged have significantly expanded in the past 25 years. Program

expansion has been due largely to the influence of at least five major federal programs with mandates for financing gerontological services: Title XVIII of the Social Security Act (Medicare), Title XIX of the Social Security Act (Medicaid), Title XX of the Social Security Act, the Older Americans Act, and the Veterans Administration. Nonprofit voluntary agencies and proprietary programs offer additional services. Because "function follows funding" (i.e., various funding sources subsidize particular kinds of services to selected client groups), the service system has been characterized as fragmented, duplicative, and replete with gaps (Steinberg, 1985). The field of gerontological home care, which primarily serves a 75 plus elder cohort, is a prime example of a category of service which is inconsistent and fragmented. Such services vary considerably in types and coverage, service duration, service eligibility, and client group served (Kaye, 1985).

The needs of growing numbers of 3 and 4 generation families that are mobile, geographically dispersed and strained to their caregiving limits with the needs of their 85 years and older relatives have received growing attention in recent years. Research has repeatedly documented that the demands of providing care to an older relative can be extremely costly and disruptive in terms of the social, psychological, and economic dimensions of family life. And, there is evidence to suggest that spouses, sons, and daughters may be reaching their absorptive capacity in terms of their engagement in the caregiving enterprise (Kaye and Applegate, 1989).

Fifth, the questionable quality, inadequate funding, short

life span, and stigma attached to many of our existing community services has especially powerful implications for an old-old cohort which is less able to maneuver about the myriad of disconnected services in the community. And, social service planners continue to have to make do with limited resources. The limited availability of funding from one year to the next has forced many public programs to adopt a defensive posture; pressing staff to their limits and operating their services on shoestring budgets. Inevitably, an organization whose lifestyle is premised on resource scarcity and a doubtful future, is subject to extraordinary tests of its capacity to operate effectively. Furthermore, there are those older adults (perhaps especially the old-old) who may be more likely to have a built-in attitudinal resistance to seeking help from public programs as well as those voluntary groups who offer services at no charge or a reduced rate (O'Brien and Wagner, 1980; Steinberg, 1985).

Finally, community workers are not only continuing to be challenged by the complexity of the very old person's personal, familial and emotional worlds, but also by a whole new set of technological advances in community-based treatment. Recent developments appear destined to further challenge the service sector and, in particular, the organizational and training regimens to which community-based personnel are exposed. Changes in the community-based service scenario seem to have been brought about by two powerful and concurrent developments.

First, is the rapid expansion in the range of in-home technologies which serve to both alter the home environment and the nature of treatment provided the homebound elderly. We have

witnessed a continuous expansion in the range of high-tech medical care which can be accessed by the older adult (Office of Technology Assessment, 1984; National Center for Health Services Research and Health Care Technology Assessment, 1988). Medical and communication technologies have been successfully miniaturized and made portable so as to enable their availability in the home of the older adult. No longer are such devices and techniques restricted to the confines of more traditional institutional settings such as hospitals and long-stay institutions. Halamandaris (1986/87) points out that "the same technology that has allowed us to save lives is now being employed to help us care for survivors." And, ever more frequently, this process of insuring survival is being played out within the natural and familiar surroundings of the home. The use of such technologies in conjunction with the appropriate design of the older person's dwelling unit can enhance the individual's "environmental fit," "competence," safety, and communications capability, all of which enable greater control over the environment (Office of Technology Assessment, 1984).

Community-based programs serving the very old in their homes can expect to witness the increasing likelihood that greater numbers of new medical procedures and devices will be utilized. Kane (1989) has pointed out that while the medical home care market remains predominantly one of service, the offering of high technology products and services represents that segment of the for-profit sector with the greatest projected rate of compound growth for sales through 1990 (17.3% compared to 12.1% for standard medical equipment and 7.1% for primary services).

Paralleling the expansion in available technology outside of the institution is the changing profile of the noninsitutionalized, frail elderly population. Home care and adult day care staff, for example, are providing service to individuals who are older, more deteriorated, and increasingly dependent on others for life maintenance. This appears to be largely due to the current economic incentive to discharge hospital patients sooner than had been the case in the past.

Many are convinced that Medicare's prospective payment system for hospital care (diagnosis related groups, or DRGs) has not only led to an expansion of such services as home health and adult day care as critical components within the gerontological service sector, but has also altered the very profile of the service population, adding to the burden of community-based programs and their staff to address the needs of an increasingly infirm aged population (Kaye, 1988). The Office of Technology Assessment (1984) has predicted that DRGs will also broaden the home use of medical care technologies, although changes in such utilization patterns will depend to a large extent on public and private reimbursement policies for home care. At the same time they caution that the lack of reimbursement and available skilled providers of care may limit access to life-sustaining technologies as well as compromise their quality and safety (Office of Technology Assessment, 1987). The recent passage of the Catastrophic Health Care Act of 1988 suggests some movement, albeit limited, in terms of establishing a reimbursement mechanism for community-based technology.

Questions of Staffing, Training, and Organizational Design

Before solutions to the changing community-based service scene can be arrived at, a number of pivotal questions need to be formulated. The questions that emerge from the service scenario which has been painted are multiple and compelling. The manner in which such fields as community home care, adult day care, senior center services, etc. respond to them may ultimately serve to determine the extent to which the oldest of our elders are adequately served. Among these questions are the following:

1) How well equipped are community service personnel to appropriately and effectively respond to the technological and accompanying ethical dimensions of care to the severely functionally impaired? To what extent do senior center staff, hospice workers, home health aides, homemakers, adult day care personnel and others possess the knowledge and skills to address these aspects of care in a responsible fashion?

2) What, if any, mechanisms have been put in place by organizations serving 80, 90, and 100 year olds in the community in preparation for the age of noninstitutional high-tech care? Have their training regimens, technical resources, and supervisory mechanisms been updated to address the informational and ethical demands which will necessarily surface during the course of service provision in the high-tech community care environment?

3) What are the respective rights of agency, client and family in the ethical decisions regarding elder patient care and the use of community-based technology? In the absence of other informal supports, what degree of agency intervention should be

taken in patient decision-making? How does the agency insure that they avoid paternalistic behavior while protecting the organization from liability?

4) To what extent should community-based agencies become involved in educating patients and families about their high-tech options? What are the incentives, if any, for agencies to develop protocols regarding decision-making about life sustaining technologies? The Hastings Center (1987) maintains that all health care institutions should have explicit policies regarding resuscitation as well as a formal process for communicating do not resuscitate (DNR) orders between institutions and emergency medical personnel. Do community care organizations serving an increasingly long-lived client population have the same responsibility? Are they creating problems for themselves by assuming such a charge or do they have a moral obligation?

5) How will community-based agencies and staff adequately discharge their responsibilities in serving the oldest of the old and manage to stay financially afloat given the current restrictiveness of noninsitutional, chronic care, reimbursement policy?

6) To what extent is a two-tiered system of care for the very old and frail elderly evolving in which there are those who have financial resources and those who depend on third party coverage? Given the dictates of DRG policy, the elderly are being pushed out of hospitals sooner and often return home in need of varying levels of intense care. Medicare will often pay for such medical care in the hospital, but not at home. Therefore, only those with money may have access to this type of

care once discharged from the hospital. Does this force those unable to foot the bill to enter nursing homes if they want to utilize medical technology?

7) Should definitions sensitive to distinctions between extraordinary and ordinary means of care in noninstitutional settings (i.e., the home) be developed as has been the case in a growing number of institutional settings? It must be kept in mind that individuals are conferred greater rights and control over their lives in their homes. Does the provision of home care services, for example, imply a compromised position for the patient in this regard? Do the laws dictating institutional care take precedence or does the individual's right to autonomy rule? Ought there to be, as proposed by Daniel Callahan, an agreed upon age that would serve as an automatic cutoff point for employing aggressive lifesaving medical equipment in the community (Callahan, 1986; Otten, 1988)?

The Future Design of Community-Based Care for the Oldest-Old

The initial charge of community care agencies serving the frail elderly may be the development of guidelines for dealing with potential ethical issues or conflicts, to determine appropriate staff roles in such cases, and to identify the organization's stance on specific ethical issues. In this regard, community agencies, in similar fashion to long-term care institutions, may need to consider utilizing ethics committees or similar governing bodies in addressing issues of medical ethics, life prolongation technologies, and determination of agency policy (Reamer, 1987).

Second, service providers will need to come to terms with the extent to which patient and caregiver education is a function of service provision. Despite increased popular attention to such matters, most elderly patients and their families have little concrete knowledge of their legal rights and responsibilities. Patients have a right to understand the availability and logistics of DNR orders and living wills, as well as their rights regarding access to and refusal of medical technology. Patient education may open a "Pandora's Box" for community administrators and staff, but there appears to be a moral obligation to enlighten consumers in this regard. Proactive rather than reactive intervention not only benefits clients, but presumably reduces the burden carried by agency personnel as well.

Community personnel need to be extremely well informed. Social and health service staff have always needed to exhibit considerable knowledge concerning the various entitlements from which the elderly may benefit. The expanding availability of a myriad of community-based technologies presents the social and health service worker with a broad range of techniques, equipment, services, and benefits of which they need to be aware. Client education should include informing program applicants and active clients of the organization's policies regarding the aforementioned technologies and the right to avail oneself of or refuse medical technologies in order to allow patients -- or their responsible parties -- to make appropriate arrangements regarding the care plan.

The organization's responsibility for education extends to the training of agency staff, particularly those with direct

responsibility for patient care. Staff need to be made aware of agency philosophy and policies as well as the protocol dictating daily procedures. In order to carry out agency policy appropriately and, when possible, the wishes of the very old, administration and staff should be aware of those clients who have active living wills, whether a proxy has been appointed, and whether DNR orders are in effect and accessible.

Providers need to keep abreast of state laws regarding withholding, withdrawing, and gaining access to technological health care and the validity of related mechanisms which promote or restrict personal choice (i.e., living wills, proxy, durable power of attorney, and DNR orders). It is likely that individuals in their eighth, ninth, and tenth decades of life and confined to their homes will be particularly uninformed about such matters.

Finally, community-based agencies serving the old-old will likely be increasingly pressed to provide or contract out for case management or service coordination services. Very old clients will more frequently require the very functions fulfilled by the case manager including periodic reassessments of their status and the appropriateness of their care plan, referral to additional or alternative service interventions, and monitoring of the quality of the linkage between the client and the service. Case management for older adults and their families has already become an increasingly common component within the human services generally, and the long-term care network in particular (Austin, 1983). Expansion of this particular service component was inspired, in part, by a series of federally-supported, long-term care demonstrations which primarily served the old-old and aimed

to expand the availability of case-managed community-based services (Capitman, Haskins, and Bernstein, 1986; Applebaum and Wilson, 1988).

Case management services are particularly important for the very-old given the complexity of service systems in most localities, the lack of standardized services, the state of flux that many programs are in, the short supply of resources to meet human needs, and the need for programs to reach the appropriate target population. Furthermore, many older persons (the eldest in particular) have not been socialized to trust or utilize human service agencies, do not know what options are available to them, and need to be steered clear of those services that may be harmful in their particular cases (Steinberg, 1985).

Serving the growing numbers of old-old within the familiar settings of their own homes and neighborhoods will challenge our long-term community care system to its limits. The extent to which the staff of the various programs comprising this system are willing to adapt and update their skills and expertise in response to the changing needs of the very old may ultimately determine whether the challenge is successfully met.

References

Applebaum, R.A. and Wilson, N.L. (1988). Training needs for providing case management for the long-term care client: Lessons from the national channeling demonstration. The Gerontologist, 28, 172-176.

Austin, C.D. (1983). Case management in long-term care: Options and opportunities. Health and Social Work, 8, 16-30.

Bould, S., Sanborn, B. and Reif, L. (1989). Eighty-five plus: The oldest old. Belmont, CA: Wadsworth Publishing Company.

Callahan, D. (1986). Health care in the aging society: a moral dilemma. In A. Pifer & L. Bronte (Eds.). Our aging society: paradox and promise. New York: W. W. Norton & Company.

Capitman, J.A., Haskins, B., and Bernstein, J. (1986). Case management approaches in coordinated community-oriented long-term care demonstrations. The Gerontologist, 26, 398-404.

Federal Council on Aging, U.S. Department of Health, Education, and Welfare. (1978). Public policy and the frail elderly. Washington, D.C.: U.S. Government Printing Office.

Halamandaris, V.J. (1986/87). A sense of the right thing to do. Generations, XI, 4.

Hastings Center. (1987). Guidelines on the termination of life-sustaining treatment and the care of the dying. Bloomington, IN: Indiana University Press.

Kane, N.M. (1989). The home care crisis of the nineties. The Gerontologist, 29, 24-31.

Kasper, J.D. (1988). Aging alone: Profiles and projections. New York, NY: The Commonwealth Fund Commission on Elderly People Living Alone.

Kaye, L.W. (1985). Homecare. In A. Monk (Ed.). Handbook of Gerontological Services. New York, NY: Van Nostrand Reinhold Publishers.

Kaye, L.W. (1988). "Generational Equity: Pitting Young Against Old." New England Journal of Human Services, VIII, 8-11.

Kaye, L.W. and Applegate, J.S. (1989). Unsung heroes? A national analysis and intensive local study of males and the elder caregiving experience. Final Report to the A.A.R.P Andrus Foundation. Bryn Mawr, PA: Graduate School of Social Work and Social Research, Bryn Mawr College.

National Center for Health Services Research and Health Care Technology Assessment. (September, 1988). Research agenda on home health care. NCHSR Program Note. Washington, D.C.: U.S.

Government Printing Office.

National Center for Health Statistics, Public Health Service. (1987). Health: United States, 1987. DHHS Pub. No. (PHS) 88-1232. Washington, D.C.: U.S. Government Printing Office.

O'Brien, J.E., and Wagner, D.L. (1980). Help seeking by the frail elderly: Problems in network analysis. The Gerontologist, 20, 78-83.

Office of Technology Assessment, U.S. Congress. (1984). Technology and aging in America. Washington, D.C.: U.S. Government Printing Office.

Office of Technology Assessment, U.S. Congress. (July, 1987). Life-sustaining technologies and the elderly. OTS Report Brief. Washington, D.C.: U.S. Government Printing Office.

Otten, A.L. (January 22, 1988). Ethicist draws fire with proposal for limiting health care to aged. The Wall Street Journal, 22.

Reamer, F.G. (1987). Ethics committees in social work. Social Work. 32, 188-192.

Steinberg, R.M. (1985). Access assistance and case management. In A. Monk (Ed.). Handbook of Gerontological Services. New York, NY: Van Nostrand Reinhold Publishers.

Zopf, Jr., P.E. (1986). America's older population. Houston, TX: Cap and Gown Press, Inc.

U.S. Bureau of the Census, U.S. Department of Commerce. (1987). March 1987 current population survey. Washington, D.C.: U.S. Government Printing Office.

Walker, S. and Harper, F. (November 15, 1986). "Successful aging: The story of centenarians." American Way, 88-93.

Zola, I.K. (1987). Home health care for older adults with disabilities. Aging Network News, IV. 6-7.